EXTENDED REPORT

6220 institutionalised people with intellectual disability referred for visual assessment between 1993 and 2003: overview and trends

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Aims: To summarise the results of visual performance tests and other data of institutionalised people with intellectual disability referred to a visual advisory centre (VAC) between 1993 and 2003, and to determine trends in these data.

Methods: A retrospective medical record review was undertaken of 6220 consecutive people examined ophthalmologically according to a standard protocol by one VAC that specialised in visual assessment and treatment of people with intellectual disability, between 1993 and 2003. χ^2 test for linear trend was used and linear regression coefficients were calculated.

Results: The proportion of people aged ⩾50 years increased from 19.3% to 34.2% between 1995 and 2003 ($p<0.001$); the combined figure of severe or profound intellectual disability decreased from 80.0% to 52.6% ($p<0.001$); the proportion of mobile people increased from 52.1% to 98.0% ($p<0.001$); the combined proportion of people with visual impairment or blindness decreased from 70.9% to 22.9% ($p<0.001$), and that of people with visual disorders decreased from 89.6% to 75.3% ($p<0.001$). Causes of intellectual disability were identified in 58.4% people; 20.8% had Down's syndrome.

Conclusion: Many ocular diagnoses were found, indicating the need for ophthalmological monitoring. Specialised centres are helpful, because assessment and treatment of people with intellectual disability is complicated and time consuming. Protocols for efficient referral will have to be developed. A major task lies ahead to improve the treatment rates of refractive errors, cataract and strabismus, and to find specific causes of intellectual disability.

Visual impairment and blindness are highly prevalent among institutionalised people with intellectual disability.[1] Visual problems often remain unrecognised in people with intellectual disability, because identifying visual problems in this group is difficult and these people rarely mention them spontaneously. Treatment and knowledge of visual problems can have positive effects on behaviour and development.[2–5] Therefore, regular assessment of visual acuity and visual fields is recommended.[6]

The present study is focused on an institutionalised population of 6220 people with intellectual disability who were referred for visual assessment between 1993 and 2003. The aim of this study is to summarise the demographic data, degree of intellectual disability, mobility, visual impairment and blindness, causes of intellectual disability, visual disorders and comorbidity, and to identify trends in these data over an 11-year period.

MATERIALS AND METHODS

Population

We retrospectively reviewed the records of 6220 consecutive people examined by the visual advisory centre (VAC) of Bartiméus, Zeist, The Netherlands, from 1 January 1993 to 31 December 2003. Bartiméus is a Dutch institution providing education, care and services to the blind and those with partial sight. The VAC was started in 1991 to identify visual problems in institutionalised people with intellectual disability, to provide information and to explore the possibilities of treatment. The first two years were omitted from the report because of small numbers of people and incomplete registration.

All subjects were people with intellectual disability living in institutions and were referred to the VAC by doctors specialised in their care. Doctors were responsible for selecting those people who could benefit from the VAC expertise—for example, those who were difficult to assess or had reduced visual performance. The ethics committee (Bartiméus, Doorn, The Netherlands) approved the study. Participants or their caretakers gave consent.

Measurements

Trained optometrists and an ophthalmologist (NTT) examined the participants ophthalmologically according to a standard protocol. Full assessment required 90 min.

Referring doctors provided personal data, data on mobility, degree and cause of intellectual disability, and medical history. Optometrists tested visual performance by assessing visual acuity and visual fields. Visual acuity was mainly binocularly measured because monocular acuity testing was often not tolerated. This had no influence on the classification of visual impairment, as acuity of the best eye was used. Visual acuity was assessed with two tests if possible: Snellen chart, Stycar or Lea Hyvärinen, and Teller or Cardiff acuity cards. The results were expressed in Snellen equivalents.

Visual fields were assessed using the confrontational method with Stycar balls. Eye movements and external eye structures were observed. The anterior segment was examined using a handheld slit lamp. Refraction was determined by retinoscopy without mydriasis.

Ophthalmological assessment by the ophthalmologist included funduscopy and retinoscopy in mydriasis, and was carried out when the cause of visual impairment was

Abbreviations: CVI, cerebral visual impairment; VAC, visual advisory centre

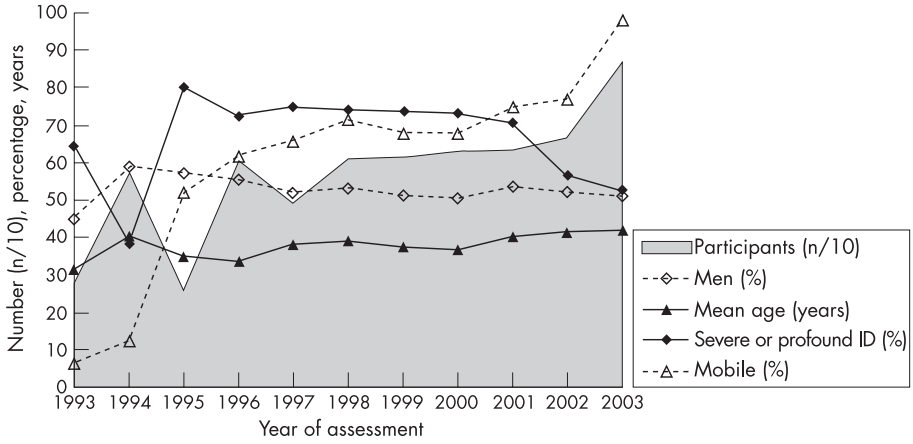

Figure 1 Trends in number of participants (n = 6220), sex (% male; n = 6217), mean age (years; n = 6211), degree of intellectual disability (% combined severe and profound intellectual disability (ID); n = 2906) and mobility (% mobile; n = 4987), according to year of assessment.

uncertain, when the question of cataract surgery arose or when retinoscopy without mydriasis seemed unreliable.

Inter-rater variability was minimal in a previous study on visual impairment among people with intellectual disability in The Netherlands, in which optometrists from the same institution as in our study carried out the assessments.[7] We therefore also assumed that inter-rater variability would be minimal in our study.

Definitions

1. Degree of intellectual disability: defined according to the *Diagnostic and Statistical Manual*, 4th edition TR classification[8]:
   - Mild, IQ 55–70;
   - Moderate, IQ 35–55;
   - Severe, IQ 25–35;
   - Profound, IQ <25.
2. Mobility:
   - Mobile, could move around independently with or without wheelchair or aids;
   - Immobile, unable to move around independently.
3. Visual performance: defined according to the World Health Organization criteria, using presenting visual acuity (modified: when visual fields were unknown, visual performance was classified according to visual acuity only; hemianopia was included, because of access to specialised care)[9 10]:
   - Normal vision, visual acuity ≥0.8 and visual fields >50°;
   - Mild vision loss, visual acuity ≥0.3 and <0.8 and/or visual fields >30° and ≤50°;
   - Moderate to severe vision loss, visual acuity ≥0.05 and <0.3, and/or visual fields >10° and ≤30°, and/or left-sided or right-sided hemianopia;
   - Profound vision loss to near blindness, light perception to visual acuity <0.05, and/or visual fields ≤10°;
   - Blindness, no light perception.
4. Refractive error: defined using the spherical equivalent of the best eye:
   - Emmetropia, spherical equivalent ≥−1D and ≤+1D,
   - Myopia, spherical equivalent <−1D;
   - Severe myopia, spherical equivalent ≤−5D;
   - Hyperopia, spherical equivalent >+1D;
   - Severe hyperopia, spherical equivalent ≥+5D.
5. Hearing impairment: defined as a loss of ≥35 dB.[11]

Statistical analyses

Demographic data, visual assessment data, causes of intellectual disability, visual disorders and comorbidity were analysed using SPSS V.10.1 and Microsoft Excel V.2002. Only data at first presentation were used. People with missing data were excluded from the analyses. When relevant, the χ^2 test for linear trend was used to assess general trends between 1993 and 2003. Linear regression analyses were used to provide coefficients (B) for significant

Table 1 Presenting visual acuity, visual fields and visual performance of people with intellectual disability (96.9%, 6030/6220)

Presenting visual acuity	Total (%)	Visual fields	Total (%)	Visual performance	Total (%)
≥0.8	1036 (17.2)	>50°	4453 (84.5)	Normal vision	1004 (16.7)
0.30–0.80	2440 (40.5)	>30–50°	446 (8.5)	Mild vision loss	2384 (39.5)
0.05–0.30	1720 (28.5)	>10–30°	265 (5.0)	Moderate to severe vision loss	1784 (29.6)
LP–0.05	521 (8.6)	≤10°	107 (2.0)	Profound vision loss to LP	604 (10.0)
NLP	312 (5.2)			Blindness	254 (4.2)
Total	6029	Total	5271	Total	6030

LP, light perception; NLP, no light perception.

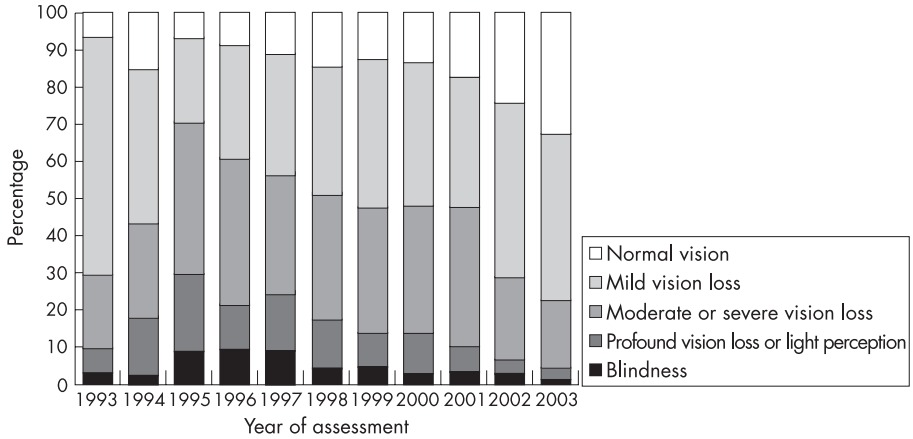

Figure 2 Trends in visual performance (%) of people with intellectual disability (6030/6220 = 96.9%), according to year of assessment.

Table 2 Specific causes (%) of intellectual disability (n = 5205)

Causes of intellectual disability	Total (%)
Down's syndrome	1081 (20.8)
Rett syndrome	71 (1.4)
Angelman's syndrome	52 (1.0)
Tuberous sclerosis	41 (0.8)
Fragile-X syndrome	24 (0.5)
Prader–Willi syndrome	12 (0.2)
West's syndrome	12 (0.2)
Cornelia de Lange syndrome	11 (0.2)
Cri-du-chat syndrome	10 (0.2)
Rubinstein–Taybi syndrome	10 (0.2)
Williams syndrome	8 (0.2)
Neurofibromatosis (von Recklinghausen's disease)	8 (0.2)
Aicardi syndrome	7 (0.1)
CHARGE association	7 (0.1)
Turner syndrome	6 (0.1)
Klinefelter's syndrome	5 (0.1)
Sotos' syndrome	5 (0.1)
Usher's syndrome	5 (0.1)
Other	145 (2.8)
Chromosomal aberration, unspecified	61 (1.2)
Total hereditary causes	1581 (30.4)
Perinatal causes (including perinatal bad condition, anoxia, asphyxia, birth trauma, haemorrhage)	644 (12.4)
Meningoencephalitis	267 (5.1)
Congenital infection, including	83 (1.6)
Rubella	37 (0.7)
Toxoplasmosis	21 (0.4)
Cytomegalovirus	15 (0.3)
Other or unspecified	10 (0.2)
Total infectious causes	349 (6.7)
Congenital hypothyroidy	21 (0.4)
Phenylketonuria	20 (0.4)
Mucopolysaccharidosis	12 (0.2)
Other	18 (0.3)
Unspecified	31 (0.6)
Total metabolic causes	97 (1.9)
Congenital anatomical brain anomalies	311 (6.0)
Prematuritas	169 (3.2)
Trauma with hypoxia or anoxia	84 (1.6)
Kernicterus	35 (0.7)
Dysmaturitas	19 (0.4)
Malignant brain tumour	8 (0.2)
Toxicosis of pregnancy	4 (0.1)
Total other causes	597 (11.5)
Unknown cause	2166 (41.6)
Total of all participants	5205

Sum of causes may exceed the respective total owing to multicausality.

trends; only values of $p<0.05$ are reported. The best value of visual acuity, visual disorders of both eyes and refractive error of the best eye were used in the analyses.

RESULTS

Population

Figure 1 shows trends in number of participants, sex, age, degree of intellectual disability and mobility, according to year of assessment. The number of participants showed a more than threefold increase between 1993 and 2003. The percentage of men was 52.7% (3275/6217) and varied between 44.9% and 58.6%. Mean age was 38.5 years (range 1.6 months–92.2 years) and increased from 35.0 to 41.9 years between 1995 and 2003 ($p<0.001$, B = +0.91 years per year). The percentage of participants ⩾50 years old was 23.5% (1460/6220) and increased from 19.3% to 34.2% between 1995 and 2003 (not shown in the figure; $p<0.001$, B = +1.8% per year).

Degree of intellectual disability was reported in 46.7% (2906/6220) of participants, of whom 63.1% (1834/2906) had severe or profound disability. This combined figure was 70.6–80.0% between 1995 and 2001, and decreased to 52.6% in 2003 ($p<0.001$, B = −4.7% per year). Mobility was noted in 80.2% (4987/6220) of participants, of whom 71.6% (3571/4987) were mobile. The percentage of mobile participants increased from 52.1% to 98.0% between 1995 and 2003 ($p<0.001$, B = +4.4% per year).

Visual impairment and blindness

Visual performance could be determined in 96.9% (6030/6220) of all participants, of whom 98.0% (5912/6030) were classified according to visual acuity and 2.0% (118/6030) according to visual fields. Moderate vision loss to blindness was present in 43.8% (2642/6030) of participants (table 1), and showed a steady decline from 70.9% to 22.9% between 1995 and 2003 ($p<0.001$, B = −5.4% per year; fig 2).

Causes of intellectual disability

Data on causes of intellectual disability, visual disorders and comorbidity were known for 83.7% (5205/6220) of participants; the other 16.3% received only a basic visual assessment without need for further exploration.

A specific cause of intellectual disability was reported in 58.4% (3039/5205) of participants (table 2). This percentage varied between 50.6% and 71.2% during the 11-year period. Down's syndrome was the most frequent cause of intellectual disability. More than one cause of intellectual disability was found in 7.2% (219/3039) of cases. Causes varied over time, but no trends were discernable.

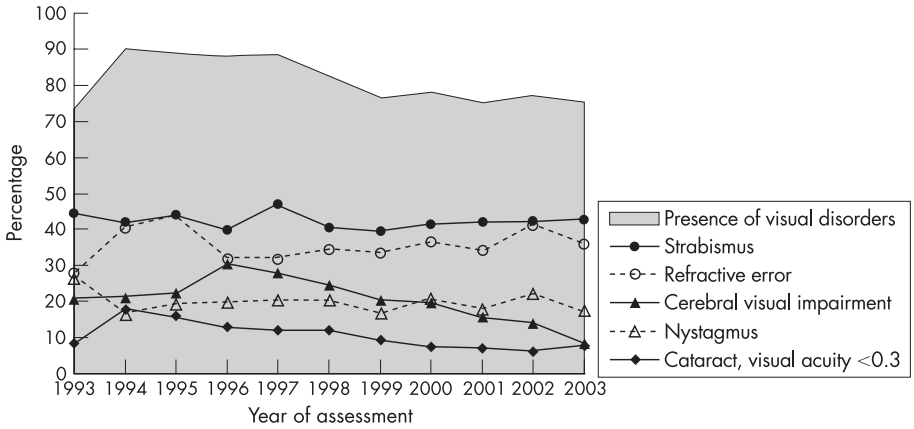

Figure 3 Trends in visual disorders (%) among people with intellectual disability (n = 5205), according to year of assessment.

Visual disorders

Visual disorders were reported in 79.9% (4157/5205) of participants. The most frequent were strabismus, refractive errors, cataract, nystagmus and cerebral visual impairment (CVI; table 3). These percentages were compared with percentages in the total population with intellectual disability and with percentages in the general population.[1 5 7 12–50]

CVI was present in 37.6% (822/2186) of participants with visual acuity <0.3, in 31.2% (210/673) of young participants (0–20 years old), and in 13.6% (343/2519) of participants aged ≥40 years. Retinoscopy was successful in 70.1% (3648/5205) of participants.

Visual disorders were present in 87.4–88.8% of participants between 1995 and 1997, and declined to 75.0–77.9% between 1999 and 2003 ($p<0.001$, $B = -1.9\%$ per year; fig 3). CVI declined from 30.3% to 8.5% between 1996 and 2003 ($p<0.001$, $B = -3.0\%$ per year) and cataract with visual acuity <0.3 declined from 17.8% to 7.7% between 1994 and 2003 ($p<0.001$, $B = -1.1\%$ per year). Strabismus (range 39.5–46.8%), refractive errors (range 27.8–44.0%) and nystagmus (range 16.5–26.4%) varied over time, but showed no specific trends.

Comorbidity

Comorbidity was present in 57.9% (3014/5205) of participants (table 4). The most frequent comorbidities were motor disability (range 24.9–39.6%), epilepsy (range 12.0–32.9%) and hearing impairment (range 4.2–19.5%). Self-mutilation of the eyes was seen in 5.4% (range 1.6–7.6%) of participants. No trends over time could be discerned.

Table 3 Visual disorders (%) among (n = 5205) people with intellectual disability

Visual disorder	This study total (%)	Population with intellectual disability (%)	General population (%)
No visual disorder	1048 (20.1)	32.5–69.4	–
Strabismus	2189 (42.1)	0.5–44.1	1.1–4.0
Myopia	1186 (22.8)	6–37	1.4–48.1
Moderate	629 (12.1)	10–25	4.3–33
Severe	557 (10.7)	3.6–27	1.3–7
Hyperopia	672 (12.9)	8–52	1.3–57.0
Moderate	556 (10.7)	24–45	30.6–42.2
Severe	116 (2.2)	1–7	0.13–3
Cataract	1270 (24.4)	2–86	0.005–57.6
VA ≥0.3	428 (8.2)	–	–
VA <0.3	497 (9.5)	–	–
Past cataract surgery	345 (6.6)	0.9–11	–
Nystagmus	1002 (19.3)	0.3–20	<0.001–0.083
Cerebral visual impairment	994 (19.1)	0.7–12.6	0.008–0.058
Keratoconus	309 (5.9)	0.1–15	0.05–<0.1
Optic nerve atrophy	203 (3.9)	2.3–24	0.019–0.13
Retinal detachment	107 (2.1)	0.7–1.3	<0.001–0.012
Atrophic bulbus or enucleation	79 (1.5)	–	–
Glaucoma	47 (0.9)	1.1–9	<0.001–8.6
An/microphthalmos	45 (0.9)	0.7–5	0.002–0.014
Tapetoretinal degeneration	45 (0.9)	0.7–4	0.003–0.027
Coloboma	35 (0.7)	0.8–3	0.001
Microcornea	29 (0.6)	2.3	–
Macular degeneration	19 (0.4)	0.7–11	0.01–40.6
Buphthalmus	8 (0.2)	–	–
Contusion of eyeball	6 (0.1)	–	–
Aniridia	3 (0.1)	–	0.001–0.002
Total of all participants	5205	–	–

Sum of visual disorders may exceed the respective total owing to occurrence of multiple disorders.
VA, visual acuity.

Table 4 Comorbidity (%) among people with intellectual disability (n = 5205)

Comorbidity	Total (%)
Motor retardation	1675 (32.2)
Epilepsy	1428 (27.4)
Hearing impairment (⩾35 dB)	647 (12.4)
Ocular self-mutilation	282 (5.4)
Diabetes mellitus	61 (1.2)
Autism	48 (0.9)
Congenital cor vitium	46 (0.9)
Hypothyroidism, acquired	40 (0.8)
No comorbidity	2191 (42.1)
Total of all participants	5205

Sum of comorbidity may exceed the total owing to multiple reasons of comorbidity.

DISCUSSION

This study on 6220 people with intellectual disability referred for visual assessment showed a steady decline in visual impairment and blindness over time. However, visual disorders remained highly prevalent. The proportion of older and mobile participants increased, and that of participants with severe or profound intellectual disability decreased. Specific causes of intellectual disability were reported in 58.4% (3039/5205) of participants.

Bias

Bias in the results of this study cannot be excluded. This is due to incomplete registration in the earlier years; these data were irretrievable.

Visual acuity was assessed with tests that are not completely comparable. However, using these different tests was the best that could be achieved in our population. The best value of visual acuity was used to classify visual impairment, without differentiating between distant and near acuity. We thought this acceptable, because near vision is the most important for most people with intellectual disability, especially for those having lower levels of functioning. The confrontational method for visual field assessment provides only an indication of the actual visual fields.

Data on causes of intellectual disability, visual disorders and comorbidity were collected from 84% of participants for whom further examination was needed. This group was more often visually impaired or blind than the other 16% (42.4% *v* 36.1%) and was expected to have more visual disorders.

Retinoscopy was successful in 70% (3648/5205) of participants. A refractive error was found in 50.6% (1845/3648) of these people. Unsuccessful retinoscopy was seen in people with severe or profound intellectual disability, with CVI or with visual acuity <0.3.

Hearing impairment was defined as a loss of ⩾35 dB in our study. This differs from the definition currently used for people with intellectual disability in The Netherlands, which also includes a mild loss of ⩾25 dB.[11] People with a loss of 25–35 dB could not be identified.

Interpretation

The threefold increase in examined people in the 11-year period is a result of increased awareness of visual impairment among caretakers and increased capacity of the VAC. Almost 25% of participants were aged ⩾50 years, which confirms previous findings of longer life expectancy of people with intellectual disability.[19 51–53] Severity of intellectual disability decreased, which may be explained by the fact that institutions with people with higher levels of functioning were referring at a later period. Increased mobility is partly caused by activation programmes.

We used presenting visual acuity in our classification, because it describes how people live their lives. A steady decline in visual impairment and blindness could be observed. The explanation might be the following. Initially, attention was focused on people with a high probability of visual impairment or blindness. Over time, the backlog of people with more severe disability became exhausted and attention shifted to those with less visual impairment. Increased awareness of the presence of visual problems among caretakers, and increased awareness of the importance of visual assessment and treatment, may have contributed to the increase in subnormal vision. Difficulties in discriminating between visual problems, intellectual disability and behavioural problems may have played a part in referral.

Despite progress in clinical investigations, no specific cause of intellectual disability was reported in >40% of people. The presence of visual disorders declined with time. This was most obvious for CVI, which was correlated to visual impairment. CVI was less often diagnosed in older people, because age-related causes of visual impairment made differentiating these people from those with CVI more difficult and because they were born before modern techniques could keep so many premature infants with brain damage alive. Refractive errors were split into subcategories, as people with moderate myopia will not have problems regarding activities of daily living. Glaucoma was diagnosed in only 0.9% of people, reflecting problems in acceptance of intraocular pressure measurement in people with intellectual disability.

Other studies

Severe or profound intellectual disability was present in 63% of our study population, compared with 55% in the total Dutch institutionalised population with intellectual disability.[54] Combined figures for visual impairment and blindness in institutionalised people with intellectual disability, reported in the literature, vary between 18.7% and 37%, compared with 44% in our study population.[19 23 35 47 48 55] This could be explained by the preselection by referring doctors. A specific cause of intellectual disability could be established in 58% of people, compared with 41–88.6% in the literature, with highest figures for severe intellectual disability.[23 28 56–60] Down's syndrome was reported in 21% of people, which is in accordance with the literature (13.1–29%).[23 48 56–59 61]

Visual disorders were difficult to compare with those reported in the literature, because populations varied greatly. They were diagnosed more often in the present study than in the total population with intellectual disability, which could be explained by preselection. Moderate hyperopia was less frequent, which could be related to definition and presbyopia not being included. CVI was related to visual impairment and severe or profound intellectual disability, explaining its higher frequencies in our study. This study confirms that visual disorders are more prevalent among people with intellectual disability than in the general population. Reported figures for the general population varied because of differences in age groups. Self-mutilation of the eyes was present in 5% of our study population. This is an important observation, because self-mutilation is a high risk factor for severe ocular morbidity.

The future

Causes of intellectual disability need further investigation, as the cause is still unknown in >40% of people. Doctors specialised in the care of people with intellectual disability and the VAC have to reach a consensus on which people will

be referred for assessment and treatment. In this way, those who could benefit most from the VAC expertise will be selected. The completion of qualify of life questionnaires would be valuable for future research, as they provide a more objective measure of therapeutic outcomes. Diagnosis and treatment of strabismus, refractive errors, cataract, ocular self-mutilation and glaucoma in people with intellectual disability will be a challenge for future studies.

Our study population is not an exact representation of the total institutionalised population with intellectual disability. However, this study showed which changes in population characteristics and visual problems may be expected after the start of large-scale visual assessment of people with intellectual disability. Although the percentage of people with moderate visual impairment to blindness decreased, >40% still had mild visual impairment. Moreover, visual disorders remained very common. We therefore emphasise the importance of visual and ophthalmological assessment of all people with intellectual disability, including those with minor impairments. Adequate assessment takes 90 min, which is not always possible in general ophthalmological practice. A VAC which is specialised in assessment and treatment of people with intellectual disability is therefore helpful in identification and treatment of visual impairment in this group.

CONCLUSION

Visual assessment of people with intellectual disability reveals abundant ocular pathology, indicating the need for ophthalmological monitoring. Specialised centres are helpful, because assessment and treatment of people with intellectual disability is complicated and time consuming. Protocols for efficient referral will have to be developed. A major task lies ahead to improve the treatment rates of refractive errors, cataract and strabismus, and to find specific causes of intellectual disability.

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Competing interests: None declared.

Ethical approval: The Ethics Committee of Bartiméus, Doorn, The Netherlands, approved the research protocol.

Subjects or their caretakers signed an informed consent for us to use their electronic records anonymously for scientific purposes.

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